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# Clinical Nurse Specialist: The Journal for Advanced Nursing Practice

## Exploring the role of key workers in cancer care: Patient and staff perspectives

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<b>Corresponding Author:</b>	Jonathan Ling, PhD, BA University of Sunderland Sunderland, Tyne & Wear UNITED KINGDOM
<b>Corresponding Author Secondary Information:</b>	
<b>Corresponding Author's Institution:</b>	University of Sunderland
<b>Corresponding Author's Secondary Institution:</b>	
<b>First Author:</b>	Jonathan Ling, PhD, BA
<b>First Author Secondary Information:</b>	
<b>Order of Authors:</b>	Jonathan Ling, PhD, BA
	Karen E McCabe, MPH, BSc
	Sue Brent, MA, BSc, RN
	Ann Crosland, PhD, BA, RN
	Lyn Brierley-Jones, PhD, BA
<b>Order of Authors Secondary Information:</b>	
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<b>Abstract:</b>	<p><b>Purpose/Aims:</b> The key worker role in cancer services was established in England to improve the continuity of care for patients. We examined how the role has been implemented by clinical nurse specialists, and how both cancer patients and nursing staff viewed its effectiveness in order to inform debate about the transfer of patients between clinical nurse specialists during cancer care</p> <p><b>Design:</b> This study was questionnaire-based, with separate surveys developed for patients and staff.</p> <p><b>Method:</b> Questionnaires explored issues including implementation of the key worker role, modifications to it, and where the role was felt to have most impact. Questionnaires were completed by 101 staff and 46 patients. Data were analysed descriptively.</p> <p><b>Results:</b> Perspectives on the key worker role differed between nursing staff respondents and patient respondents. Overall, patient respondents were very positive while staff respondents were less so. A key difference related to patient handover: 71% of patient respondents wanted the same key worker throughout their treatment but only 28% of staff respondents did. Staff respondents wanted more training to clarify the role.</p> <p><b>Conclusions:</b> Continuity of care through an assigned key worker was highly valued by patients. Successful implementation could be better achieved through improved communication with both nursing staff and allied health professions. Where possible, cancer patients should be assigned a dedicated key worker at initial diagnosis.</p>



**University of  
Sunderland**

**FACULTY OF APPLIED SCIENCES**

FLEMING BUILDING  
CITY CAMPUS  
SUNDERLAND SR1 3SD  
UNITED KINGDOM

TEL: 0191 515 3496  
FAX: 0191 515 2175  
[www.sunderland.ac.uk](http://www.sunderland.ac.uk)

4 March 2017

Dear Prof. Fulton

Please find enclosed a further revised version of our paper 'Exploring the role of key workers in cancer care: Patient and staff perspectives'. We have made the final amendment requested by Reviewer 2 - changing 91.1% to 7.9% on page 6. No other changes have been made to the files.

Many thanks for considering our paper for publication in Clinical Nurse Specialist, and great thanks to the reviewers for their insightful comments.

Yours sincerely,

Jonathan Ling



**DEAN**  
**PROFESSOR JOHN MACINTYRE**  
PhD BSc (Hons) FRSA MBCS CEng  
DTI/HEFCE National Business Fellow

**VICE-CHANCELLOR AND CHIEF EXECUTIVE**  
**PROFESSOR PETER FIDLER**  
MBE DL MSc DipTP DipSoc MRTPI MInstD

## Exploring the role of key workers in cancer care: Patient and staff perspectives

Jonathan Ling<sup>1\*</sup>, PhD, BA, Karen McCabe<sup>1</sup>, MPH, BSc, Sue Brent<sup>1</sup>, MA, RN,  
Ann Crosland<sup>1</sup>, PhD, BA, RN, Lyn Brierley-Jones<sup>2</sup>, PhD, BA

<sup>1</sup> School of Nursing and Health Sciences, University of Sunderland, Chester Road,  
Sunderland, SR1 3SD, UK (e-mail: [Jonathan.ling@sunderland.ac.uk](mailto:Jonathan.ling@sunderland.ac.uk)).

<sup>2</sup> Independent researcher

\* Corresponding author. Prof. Jonathan Ling, School of Nursing and Health  
Sciences, University of Sunderland, Chester Road, Sunderland, SR1 3SD, UK  
[jonathan.ling@sunderland.ac.uk](mailto:jonathan.ling@sunderland.ac.uk), +44 (0) 1915153496.

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RE: CNS 16-75, entitled "Exploring the role of key workers in cancer care: Patient and staff perspectives"

Response to Reviewer Comments:

**Reviewer #1:** This is much improved and much clearer-I would recommend publication

- Thank you for this comment.

**Reviewer #2:** Your revisions are well done and your manuscript now is much clearer and easier to follow, and very clearly applicable to CNS practice. However, there is one point that needs clarification. On page 6, line 29, you state "Very few" but then provide the percentage as 91.1%. That doesn't make sense. Can you please make whatever correction is needed?

- Apologies, and thanks once again for this close and helpful reading of our work. We have changed the number presented in the text on page 6 to 7.9% to better match the phrasing.

# Exploring the role of key workers in cancer care: Patient and staff perspectives

## Exploring the role of key workers in cancer care: Patient and staff perspectives

**Purpose/Aims:** The key worker role in cancer services was established in England to improve the continuity of care for patients. We examined how the role has been implemented by clinical nurse specialists, and how both cancer patients and nursing staff viewed its effectiveness in order to inform debate about the transfer of patients between clinical nurse specialists during cancer care

**Design:** This study was questionnaire-based, with separate surveys developed for patients and staff.

**Method:** Questionnaires explored issues including implementation of the key worker role, modifications to it, and where the role was felt to have most impact. Questionnaires were completed by 101 staff and 46 patients. Data were analysed descriptively.

**Results:** Perspectives on the key worker role differed between nursing staff respondents and patient respondents. Overall, patient respondents were very positive while staff respondents were less so. A key difference related to patient handover: 71% of patient respondents wanted the same key worker throughout their treatment but only 28% of staff respondents did. Staff respondents wanted more training to clarify the role.

**Conclusions:** Continuity of care through an assigned key worker was highly valued by patients. Successful implementation could be better achieved through improved communication with both nursing staff and allied health professions. Where possible, cancer patients should be assigned a dedicated key worker at initial diagnosis.

## Exploring the role of key workers in cancer care: Patient and staff perspectives

### INTRODUCTION

Patients with cancer face a physically and mentally demanding journey with their disease. Several interventions have been developed to support patients as they move along a care pathway (see eg Yates, 2004) and may lead to improved patient experience particularly when offered early in care (Wagner et al., 2014). However, these interventions are often accompanied by a lack of clarity in relation to roles and responsibilities (Brogaard et al., 2011), for example whether the interventions should involve only the coordination of care, or whether there should also be an element of brokerage/advocacy incorporated into them. One such intervention is the key worker role which was first developed in the England as a means of ensuring continuity of care for patients by specifying a member of their care team as the main point of contact between health and social care (Department of Health, 2007). In England, the key worker role combines both care coordination and case management which have often been separate in cancer care (Borras et al., 2014). While the role as initially conceived allowed any health care professional to become a key worker, in practice for cancer this has usually been a clinical nurse specialist.

Previous work has identified the central role of nurses in the provision of information to patients, particularly after treatment has been initiated (see Koutsopoulou et al., 2010, for a review), with nurses often being patients' primary source of information (Friis et al., 2003). A primary role of the key worker is the provision of information and support to patients (Martins et al., 2014). Although the key worker role does show promise for supporting patients (Vidall et al., 2011), lack of clarity in relation to the roles and responsibilities of key workers, as well as identifying key workers themselves are important issues within palliative care (Brogaard et al., 2011).

While the role of the key worker is becoming used more widely in healthcare (Clarke, 2013; Gadoud et al., 2013), in the United Kingdom (UK), the role has been integrated most closely with treatment for cancer. This is due partly to the complexity of treatment for patients with cancer who are often under the care of several health teams (oncology, surgery, palliative care, etc.). Until recently, the importance of coordinating patient care across multi-disciplinary teams from the perspective of staff or patients had not been widely recognised. To address this issue, the role was developed as a mechanism to promote continuity of care for cancer patients (Gysels et al., 2004) and has been



integrated into national guidance for the treatment of cancer (eg Department of Health, 2010; Independent Cancer Taskforce, 2015)). The key worker role was developed as part of the portfolio of work undertaken by specialist cancer nurses (while staff who are not cancer nurses can become key workers, in this study we focus only on cancer nursing staff who are key workers). Specialist cancer nurses have several responsibilities, including the provision of clinical interventions, clinical or practical advice and emotional support to patients. Specialist cancer nurses can have a central role in case management, in particular acting in a brokerage role to improve the quality and treatment of patients in cancer care pathways (see eg Wulff et al., 2008). ; However, little work has examined how the keyworker role has been implemented by practitioners, or how the role is perceived by staff or patients.

The aim of this study was therefore to explore the perceptions of both staff and patients of the key worker role in cancer care in order to inform implementation of the role and delivery To achieve these aims we had several objectives:

- to explore the key worker role from the perspective of oncology staff in relation to how the role was implemented
- determine whether specific training for the key worker role was given and the extent to which staff felt this role impacted their ability to carry out other aspects of their jobs
- establish how such specific roles should be developed and implemented by clinical nurse specialists within oncology nursing, whether the role should transfer to other staff (such as physiotherapists) when patients move along a care pathway
- evaluate whether the specific role of key worker is valued by patients, and how patients made use of the key worker.

## METHODS

### *Design*

Data were collected using structured questionnaires. Questions were based on themes drawn from an earlier qualitative study with oncology staff and patients who had cancer (Ling et al., 2013). A pilot study was conducted where draft questionnaires were given to patients and staff for review before final versions were produced based on their feedback. None of the participants in the pilot study were included in the main study. The staff questionnaire was circulated electronically to all clinical

nurse specialists working as key workers in cancer care from participating National Health Service (NHS) Trusts for anonymous electronic completion. Anonymous postal questionnaires were sent to a convenience sample of cancer patients for completion and return. Patients were selected by staff in order to ensure that they were well enough to complete the questionnaires. In order to obtain a maximum variation sample in terms of stage of treatment and cancer type, we approached staff from across the north of England and with different cancer specialisms in order to get access to as diverse a range of cancer patients as possible.

### *Ethics*

This project was hosted and funded by the North of England Cancer Network and sponsored by NHS South of Tyne and Wear. Ethical approval for this study was granted by Northern and Yorkshire NHS Research Ethics Committee and the lead author's university. All questionnaires were returned anonymously. All participants were provided with information about the study which clarified that their participation was voluntary and that they could refuse to participate, without giving any reason, without their rights being affected. As participants were asked to submit the questionnaire anonymously either online or by post (via a prepaid envelope), submission was taken as confirming consent.

### *Participants*

*Staff:* In total, 101 questionnaires were completed by staff. This represented a response rate of 49.5% (based on 204 Clinical Nurse Cancer Specialists across the region who received the questionnaire).

*Patients:* Patients returned 46 questionnaires out of 200 that were distributed, a response rate of 23%.

### *Materials*

Separate questionnaires were developed for staff and patients based on issues raised by staff and patients in exploratory interviews in relation to cancer care (see Ling et al., 2013). The questionnaires were devised by the research team and piloted with several staff and patients for face validity and to establish that the questions were meaningful. Based on this feedback, minor changes were made before the questionnaires were distributed. The staff questionnaire consisted of 30

statements covering areas such as evaluation of the key worker role, process and implementation, role management and use of the term. The patient questionnaire consisted of 20 questions related to the issues patients had contacted their key workers about, whether they wanted to retain the same key worker throughout their treatment and their views of the role. Most statements were responded to using a 4-point Likert scale from strongly agree to strongly disagree, with others requesting binary responses, such as 'Have you heard of the term 'key worker'?'. In addition, both the staff and patient questionnaires asked for general demographic information (age, sex), as well as cancer specialism (for staff) or type of cancer (for patients). The questionnaires also included free text boxes for respondents to add further comments about the key worker role specifically and another box for them to add any further comments if they wished.

### *Data analysis*

Data were entered into an SPSS (version 22.0) database for analysis. Descriptive statistics, such as frequency distributions, were used to describe and summarise the characteristics of the sample and the variation in responses. Responses of Strongly Agree and Agree were aggregated, as were Strongly Disagree and Disagree. All data that had Likert or Yes/No responses are reported in the tables, with the remaining statements reported in the text. Free text responses were analysed thematically.

## **RESULTS**

Of the nurse respondents, 99 were female, with a mean age of 46 years (SD: 6.71; range = 30–61). Respondents had worked in cancer care for a mean of 13 years (SD: 6.36; range: 8 months–31 years). They worked across a wide range of cancer specialisms, with the most common being palliative (19.8%), colorectal (14.9%) and breast (13.9%).

Patient respondents had a mean age of 63 years (range: 22–84) and the majority was female (58.7%;  $n = 27$ ). Participants had been diagnosed with cancer on average two years before the survey took place (range: 1 month to 11 years, 11 months). The most frequently reported form of cancer was breast (23.9%;  $n = 11$ ), followed by bowel (13%;  $n = 6$ ) and then lung and prostate (both 10.9%;  $n = 5$ ). Patient respondents varied in the stage of their cancer, with the largest group receiving some form of treatment at the time of the survey (43.5%;  $n = 20$ ), followed by those who had completed their treatment (34.8%;  $n = 16$ ), with the remainder either discharged (15.2%;  $n = 7$ ) or at early

diagnosis (4.3%;  $n = 2$ ).

## **Staff views of the key worker role**

### ***Role introduction and processes***

For many staff respondents, the key worker role was first explained to them at a cancer-site specific group meeting ( $n = 34$ ; 33.7%). Other staff respondents had the role introduced at a hospital meeting (20.8%;  $n = 21$ ), by their line manager (16.8%;  $n = 17$ ), or other colleague (17.8%;  $n = 18$ ). For some (10.9%;  $n = 11$ ), the role had only been introduced to them informally.

Most (78.2%;) staff respondents reported that their organisation had a key worker policy (Table 1). Of those reporting that their organisation had a policy, some accessed it via lead cancer nurses (44.6%;  $n = 45$ ), an intranet (33.7%;  $n = 34$ ), multidisciplinary team (MDT; 28%;  $n = 29$ ), Human Resources (3%;  $n = 3$ ) or other (9%;  $n = 9$ ).

Very few (7.9%) staff respondents reported having received any training for the key worker role. A sizeable minority (46.5%) were neutral over whether the role had been communicated well to them (see Table 1), with more disagreeing that it had than those who agreed. Most staff respondents (51.5%) agreed that they thought training was necessary to implement the role, however their most frequent response was neutral in relation to whether the role had changed their workload (44.6) practices.

[Table 1 about here](#)

### ***Implementation of the role***

A small majority of staff respondents agreed that the role had been successfully implemented (51.5%; Table 1). The most frequent response to whether paperwork in relation to the administration and linking with other practitioners had increased (35.6%). Most staff respondents (56.4%) reported that the role had formalised existing working practices but were ambivalent about how the role had been embraced by allied health professionals (37.9%). Most staff respondents (78.2%) reported that

adopting or incorporating the key worker role into their existing practice had no impact on the time they spent with patients.

### ***Role allocation***

Respondents reported that most decisions as to who would initially take on the key worker role were made by a staff member present at diagnosis (50.5%;  $n = 51$ ), although decisions were also made by the MDT (18.8%;  $n = 19$ ). Several staff respondents (25.7%;  $n = 26$ ) reported a range of practices for the allocation of a patient's initial key worker. These included allocation according to the geographical location of the patient (3 responses), or to staff with specific roles (10 responses) such as specialist cancer nurses. In other instances, it was stated that specified staff *always* became key workers (4 responses) because, for example, they were lone workers or the only nurse with available time. Two staff respondents also reported that patients could request an individual to be their key worker and one reported that the role was allocated to any member of staff who had capacity. Six stated that they did not know how the key worker role was allocated.

### ***Transfer of the role***

Two thirds of the staff respondents surveyed disagreed that the same key worker should stay with the patient throughout their journey (Table 2). A majority of staff respondents agreed that the role of the key worker should extend beyond the end of a patient's treatment. Most staff respondents felt that the role of the key worker changed over the course of a patient's illness. In response to the question of whether the role was useful for them in their professional practice, similar proportions of respondents agreed or gave neutral responses. The most frequent choice (38.6%) was neutral for whether the term 'key worker' was useful.

### **Table 2 about here**

In response to the question 'Where should information related to a patient's key worker be recorded?', the majority of respondents selected case notes 90.1% ( $n = 91$ ), as well as their own records 76.2% ( $n = 77$ ). Electronic notes were also selected by 47.5% ( $n = 48$ ) of staff respondents.

Other places for the key worker information to be noted was an option chosen by 9.9% ( $n = 10$ ), with further suggestions including an MDT form, letters or faxes to general practitioners or a card containing important key worker information. One respondent noted that the identity of a patient's key worker was not always shared between primary and secondary care.

### ***Key worker term***

There was little difference between the number of staff respondents who identified themselves to patients as their key worker and those who did not (43.6% cf 54.5%; Table 2). Few staff respondents used the term when discussing patients with colleagues, with those that did not use it referring to themselves by their specific job title, such as lung cancer nurse specialist.

The introduction of the key worker role had not impacted on the roles of most staff respondents, and a sizable majority reported that patients did not use the term when contacting them.

### **Patient views of the key worker role**

#### ***Views of the key worker role***

Most (84.8%) patient respondents had heard of the key worker role (Table 3). Of those that had heard of the term, 25 had heard about it in hospital, and nine from other places such as the media. Two patient respondents had only heard about the role when asked to complete the questionnaire and three gave no answer. Nearly all patient respondents reported having a key worker and for most (82.6%) their key worker had not changed over the course of their treatment.

The majority of patient respondents disagreed with the statement that key workers should change over the course of their treatment, preferring continuity of care. Patient respondents also wished that the role of the key worker would extend beyond the end of treatment. Most patient respondents agreed that both the key worker role and the key worker term were useful. Patient respondents contacted their key workers most frequently by telephone (73.9%;  $n = 34$ ) or in person (8.7%;  $n = 4$ ). None reported contacting their key worker by email or by post and several reported that they did not contact their key worker at all (10.9%;  $n = 5$ ).

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4 Patient respondents felt that the point in treatment that they would benefit most from a key worker  
5 was early diagnosis (45.7%;  $n = 21$ ), followed by initial treatment/appointments (30.4%;  $n = 14$ ).  
6 After completion of treatment (8.7%;  $n = 4$ ) and when treatment changed (2.2%;  $n = 1$ ) were chosen  
7 by few respondents. Three participants selected 'other' as a response; all stated that there was no  
8 most helpful time for a key worker – that they would be helpful throughout the care pathway.  
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17 Table 3 about here  
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22 Patient respondents reported contacting their key worker with questions about their treatment  
23 (78.3%;  $n = 36$ ), questions about cancer (64%;  $n = 29$ ), or other health questions not directly related  
24 to cancer (32.6%;  $n = 15$ ), making an appointment for the key worker themselves (23.9%;  $n = 11$ ) or  
25 with someone else (28.3%;  $n = 13$ ). Patient respondents identified the key worker role as reassuring,  
26 providing a central point of contact, a specialist in their field who was also a familiar face and who  
27 knew who they were and was aware of their experiences and treatments to date. Patient respondents  
28 valued having a specialist they could contact directly and easily. The majority of patient respondents  
29 did not use the term key worker when contacting the hospital or other health professionals (73.2%;  $n$   
30 = 30 *cf.* 26.8%;  $n = 11$ ), but rather just asked for their key worker by their first name.  
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40 The two free text questions asked first whether patient respondents had any specific comments about  
41 the key worker role. Of the 101 patients who returned questionnaires, 37 gave responses. Responses  
42 were overwhelmingly positive:  
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46 *It is reassuring that you have someone to contact to help with any issues you have. It is*  
47 *comforting to know that when you attend a clinic you already know a friendly face. It helps*  
48 *your confidence. A shoulder to cry on, she gave me great support*  
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52 In particular, patient respondents focused on the importance of having a single point of contact  
53 throughout their treatment, which some felt had improved the outcome of their treatment:  
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57 *Val, my key worker has been at my side on the cancer journey from diagnosis, through*  
58 *surgery, chemo[therapy], radio[therapy] and beyond. She has a thorough knowledge of my*  
59 *background, temperament, circumstances and has been crucial to my recovery.*  
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The second free text question asked for ‘Additional comments’ and 21 patient respondents gave responses. Again, most of these comments related to positive views of the key worker role.

*Staff at [the hospital] were excellent, they were very organised and professional. My key worker made my experience run smoothly and as less stressful as she could. She played a vital part in my treatment. A role that MUST be continued.*

Although the use of the key worker term by staff was not absolute, as a small number of patient respondents reported unfamiliarity with the term:

*I have never considered my oncologist as a "key worker" as the term has been alien to me. Perhaps it should have coined, and used, from the outset of my treatment?*

## DISCUSSION

This study used questionnaires to explore how cancer nursing staff and cancer patients viewed the key worker, as well as examining how the role was implemented within cancer services. Two key, and somewhat contrasting, messages emerged from this work. First, staff respondents saw the role as adding to the administrative burden of their roles, and felt that it should be transferred as patients moved through the care pathway. Second, and in marked contrast, patient respondents stated they placed significant importance on the relationship that they developed with their key worker as they moved along the cancer pathway. Below, we discuss some of the possible reasons for the difference in perspectives of staff respondents and patient respondents, but first we examine the implications of our results for the implementation of the key worker role.

### Implementation

According to both national (National Cancer Action Team, 2011) and regional (NECN, 2010) guidance, key workers should be allocated to patients on the basis of discussions taking place within MDT meetings when initial diagnosis and treatment planning decisions are discussed. Staff respondents in this study reported that this happened infrequently, and that decisions related to the allocation of the key worker role was usually made by the clinical nurse specialist present at diagnosis. This divergence from guidance may be for a variety of reasons. These reasons may include lack of knowledge of national or regional guidance or local key worker policies, pragmatic reasons, such as allocating patients to staff who may have space in their workloads, or always



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4 allocating new patients to a specified individual.  
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7 Unevenness in the provision of the cancer nurse specialist role across regions has been identified  
8 elsewhere (Vidall et al., 2011). However, while staff respondents in the present study were generally  
9 positive about the way in which the role had been implemented, this varied across cancer site and  
10 geographic location. The main issue was one related to the introduction of the key worker role to  
11 staff. For example, reported knowledge of the role was variable, with many respondents incorrectly  
12 reporting that their organisation had no key worker policy when they were already publicly available  
13 online. We also found that while most staff respondents felt that training was necessary to  
14 implement the key worker role effectively, few reported having received any.  
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22 There were some equivocal in the data. For instance, while there was a general consensus among  
23 staff respondents that the key worker role had led to no change in their working practices, most  
24 nurses reported it had increased paperwork and workload. This is likely to mean that staff do not  
25 consider paperwork as being a central part of their role, so when stating that their nursing role has  
26 not changed, they may be referring to direct patient care, rather than the administrative aspect of  
27 their practice.  
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### 34 **Staff and patient views of the key worker role** 35 36

37 One issue that emerged from the questionnaires was that many staff respondents felt that the key  
38 worker role was little more than a re-titling of existing working practices in the sense that it  
39 formalised already existing work practices. This was reflected in staff responses, in that the role was  
40 reported as having little impact on overall workload other than an increase in associated paperwork.  
41 Such beliefs about the value and implementation of the role may have been related to the  
42 inconsistency in the way in which the role had been communicated.  
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49 The transfer of the key worker role from one member of staff to another marked the area of greatest  
50 divergence between the views of staff respondents and patient respondents. The majority of staff  
51 respondents felt that the role of key worker should transfer as patients progressed through different  
52 stages of treatment because of the changing requirements of a patient's care and that the role should  
53 also continue after discharge, which corresponds with the majority of patient respondents who  
54 expressed a wish for the role to continue. Despite staff respondents stating that they felt the key  
55 worker role should transfer, the overwhelming majority of them did not do this. This could have  
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4 occurred for a variety of reasons, one of which was lack of buy-in from allied health professionals,  
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6 or because they felt a duty of care to ‘their’ patients (see Ling et al., 2013).  
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9 The ambiguous views of staff respondents contrasted markedly from those of the patient  
10 respondents. Patient respondents were very positive in relation to the care they received from their  
11 key worker. For patient respondents, continuity and coordination of care were paramount. Very few  
12 patient respondents stated that they would have liked their key worker to change as they moved  
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14 along the care pathway. What this appears to demonstrate is that, for patients, being able to contact a  
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16 named individual who had competence within cancer though not necessarily expertise in every  
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18 aspect of cancer and its treatment was felt to be of most benefit. What was unclear was the degree to  
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20 which patient respondents saw the value of the role itself. In other words, would the care  
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22 experienced by patients have been any different if they had not been assigned a key worker? We  
23  
24 believe that it would. In earlier work, researchers reported that the comfort of having an assigned  
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26 member of staff to take patients through their cancer journey from diagnosis, to treatment and  
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28 beyond was of immense importance to patient respondents, and legitimised their making contact  
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30 with them (Ling et al., 2013). This reflects both the need for the ‘constant factor’ (Dean, 2006) in  
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32 patient care, as well as the need for clear, patient-centred communication (Mazor, et al., 2013). Our  
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34 recommendation would be that the role be retained as a central element of cancer care. It is also  
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36 likely that this role would be beneficial for other conditions such as stroke which are characterised  
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38 by care from a wide range of practitioners. This work also supports previous findings about the use  
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40 of case management in cancer pathways to optimise treatment and care for people with cancer  
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42 (Wulff et al., 2008), where patients were very positive about the impact of the key worker role. No  
43  
44 clear pattern emerged for whether the role had strengthened relations between staff and patients.  
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46 However, in free-text comments added to the end of the patient questionnaires, patients were highly  
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48 complimentary of both the staff and the care they had received.  
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50 Our findings also provide evidence to support some of the concerns raised by nurses prior to the  
51 introduction of the key worker role (Hitchen, 2009) in terms of the time and resources needed to  
52 implement it. Future work should consider the direct and indirect costs in relation to the introduction  
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54 of the role because of their implications for nursing resource management.  
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## 58 **Recommendations for the development of the key worker role**

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### ***Training and communication***

The survey showed that improving awareness of the key worker role among patients and clarifying the aims and responsibilities of the role with staff is needed. Part of this should be an acknowledgement of existing best practice as well as an emphasis that the aims of the key worker role should map on to this practice. For patients, key worker information should be provided at initial diagnosis.

### ***Allocation of patients to clinical nurse specialists***

Most patient respondents who expressed a preference wanted to retain the same key worker over the course of their treatment. However, such allocation may be impractical for breast and other types of cancer where there are large numbers of patients, or head and neck cancers where there are multiple, diverse specialists working with patients throughout the course of their care. Long-term follow up of patients would also be potentially aided if they were to retain their key worker (Skinner et al., 2007). Given this, as well as the importance to patients of continuity in their care, patients should be allocated to the staff who would be able to retain patients for the longest period of time.

### **Limitations**

This survey focused on cancer care, however the initial aim of the key worker role was to be the main point of contact between health and social care (Department of Health, 2007). Therefore we are unable to say whether key workers were expected to make the link between primary and secondary care, and if they do, how this happens in practice. This should be examined in further work because it has implications for staff, both in terms of their time as well as the potential need for further training, as well as for patients in terms of the expectations they might have of the key worker role.

The response rate from the staff respondents to the questionnaire was acceptable, with half of the clinical nurse specialists from across the region responding. Thus, the responses are likely to be reasonable reflections of opinions of the key worker role. The response rate from the patient group was low, though this is perhaps not surprising for a postal questionnaire from patients most of whom were still undergoing treatment for cancer, nonetheless such a response rate limits the strength of the recommendations we are able to make based on their responses, as well as their generalisability.

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4 Patients were approached by clinical nurse specialists or nurses in palliative care to act as  
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6 participants. We adopted this approach to patient recruitment to minimise potential distress to  
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8 patients and their families, such as through asking a gravely ill patient to complete the questionnaire.  
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10 While there are obvious problems with this in relation to introducing bias, we believe that the patient  
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12 sample was chosen with care by the nursing staff in order to represent a range of viewpoints. We  
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14 believe that this did occur, as evidenced by several patient respondents reporting that they had not  
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16 heard of the key worker role prior to completing the questionnaire. Nonetheless, future work should  
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18 aim to replicate our findings by sending questionnaires to all patients from a list of those deemed  
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20 well enough to participate.

## 21 **Conclusions**

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24 Staff and patient respondents had markedly different views of the value of the key worker role. Staff  
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26 respondents saw the role as one which they felt should transfer to other staff, while patient  
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28 respondents placed a great value on the role, wanting to retain the same key worker throughout their  
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30 care. Further work is needed to develop and disseminate policy in relation to the key worker role for  
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32 clinical nurse specialists, but the importance of the role from a patient perspective should encourage  
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34 the uptake of this role more widely.  
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*Table 1: Staff views of training and impact of the key worker role on working practice.*

	% (N)	% (N)	% (N)	% (N)	% (N)
	Yes	No	Don't Know		
Does your organisation have a key worker policy?	78.2 (79)	20.8 (21)	1 (1)		
Have you had any training for the key worker role?	7.9 (8)	91.1 (92)			
	Less time with patients 2 (2)	No impact on time spent with patients 78.2 (79)	More time with patients 12.9 (13)		
Has the key worker role led to:	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
The role was well communicated to staff	9.9 (10)	19.8 (20)	46.5 (47)	16.8 (17)	5 (5)
Training was necessary to implement the role	4 (4)	13.9 (14)	30.7 (31)	42.6 (43)	8.9 (9)
Do you think that the key worker role has...:					
Been implemented successfully	4 (4)	13.9 (14)	30.7 (31)	42.6 (43)	8.9 (9)
Increased paperwork	4 (4)	18.8 (19)	35.6 (36)	30.7 (31)	5.9 (6)
Increased workload	5.9 (6)	23.8 (24)	44.6 (45)	14.9 (15)	5 (5)
Has formalised already existing working practices	6.3 (6)	15.6 (15)	21.9 (21)	45.8 (44)	10.4 (10)
Has been embraced by staff from allied health professions	9.4 (9)	35.7 (34)	37.9 (36)	15.8 (15)	1 (1)
Has strengthened relations between staff and patients	12.4 (12)	21.9 (21)	37.5 (36)	25 (24)	4.1 (4)
The key worker role changed your working practice	14 (14)	25 (25)	43 (43)	17 (17)	1 (1)

*Note:* For all tables and text, percentages are given first, with frequencies in brackets. Some participants did not complete all questions, therefore frequencies do not always add up to 101.



Table 2: Staff views of flexibility and usefulness of the key worker role.

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
	% (N)	% (N)	% (N)	% (N)	% (N)
The key worker role should stay with the same member of staff throughout the patient's journey.	16.8 (17)	49.5 (50)	5.9 (6)	21.8 (22)	5.9 (6)
Your role has changed since the introduction of the key worker role.	12.1 (12)	44.4 (44)	29.3 (29)	12.1 (12)	2 (2)
Patients use the term 'key worker' when contacting staff.	40 (28)	23.2 (23)	16.7 (16)	2 (2)	1 (1)
A patient's key worker should change according to the stage of their illness.	6 (6)	12 (12)	12 (12)	50 (50)	20 (20)
A key worker role should extend even after the end of the patients' treatment	4 (4)	11 (11)	16 (16)	51 (51)	18 (18)
In your experience does the role of the key worker change over the patient's journey?	2.2 (2)	10.9 (11)	15.8 (16)	61.4 (62)	9.9 (10)
Overall, the key worker role is useful for you in your professional practice	7.9 (8)	10.9 (11)	35.6 (36)	38.6 (39)	5 (5)
The 'key worker' term is useful	17.8 (18)	17.8 (18)	38.6 (39)	17.8 (18)	0
	Yes	No	Don't know		
Do you use the key worker term with patients (eg do you identify yourself to patients as their key worker)?	43.6 (44)	54.5 (55)			
Do you use the key worker term when discussing the patient with colleagues (such as phoning up someone and asking for a patient's key worker)?	21.8 (22)	76.2 (77)			

Table 3: Patient views of the key worker role.

	% (N)	% (N)	% (N)	% (N)	% (N)
	Yes	No	Don't know		
Have you heard of the term key worker?	84.8 (39)	15.2 (7)			
Do you have a key worker?	89.1 (41)	8.7 (4)	2.4 (1)		
Has the person who is your key worker changed over the course of your treatment?	82.6 (38)	10.9 (5)			
	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
	% (N)	% (N)	% (N)	% (N)	% (N)
Do you think your key worker should change over the course of your treatment?	35.7 (15)	35.7 (15)	23.8 (10)	2.4 (1)	2.4 (1)
The key worker role should stay with the same member of staff regardless of stage of treatment.	4.8 (2)	2.4 (1)	21.4 (9)	35.7 (15)	35.7 (15)
The key worker should change according to the stage of illness	24.3 (10)	43.9 (18)	19.5 (8)	7.3 (3)	4.9 (2)
The role should extend even after the end of treatment.	0	4.9 (2)	7.3 (3)	46.3 (19)	41.4 (17)
The term 'key worker' is useful.	4.9 (2)	7.3 (3)	19.5 (8)	58.6 (24)	9.8 (4)
The key worker role has been helpful.	2.4 (1)	2.4 (1)	2.4 (1)	45.9 (17)	52.4 (22)